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ABSTRACT

This theme issue addresses emotional and social issues faced by children and their families across a number of disability areas, with emphasis on needs the disabled have in common with all people, the value of tangible and emotional support for all family members, the need for comprehensive services, and the expertise that families can bring to professionals developing services. The following brief articles are included: "Emotional Problems among Children Who Are Blind or Have Severe Visual Impairments" (J. Elton Moore); "Preventing Mental Health Problems in Children with Chronic Illness and Disability" (Joan Patterson); "Families and Children with Traumatic Brain Injury" (Betty Pieper); "Childhood Trauma Is Two Stage Crisis for Families" (Marilyn Lash); "Children with Deafness and Mental Health Concerns" (Mimi W. P. Lou); "Children with Developmental and Psychiatric Disorders" (Dee Kruger); and "New Developments Increase Access to Supplemental Security Income (SSI) Benefits for Children with Disabilities." (DB)

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FALL 1990/WINTER 1991

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FOCAL POINT

Social and Emotional Supports for Children with Disabilities and Their Families

In this issue we feature discussions of the emotional and social support needs of children who have chronic illnesses, or physical or developmental disabilities and their families. We have been interested in the parallel developments in family support across disability fields for some time, and this interest was sharpened by an October 1990 meeting of directors of projects funded by the National Institute on Disability and Rehabilitation Research (NIDRR) in which many concerns related to family involvement and family support were explored. As we have become acquainted with families whose members have a variety of disabilities, we are impressed by the common issues faced by families across disability type and geographic region of the country. These include needs for information and social support as well as the challenges of balancing family life so that the needs of all members are addressed.

Although families dealing with disabilities have much in common, there are also specific issues related to the type of disability, as well as to the circumstances and preferences of families. For this reason we solicited articles addressing emotional and social issues faced by children and their families across a number of disability areas. These include hearing impairment and deafness, low vision or blindness, traumatic brain injury, physical trauma, chronic illness in children and adolescents, and developmental disabilities. Along with the disability-specific information and guidance about how best to address the social and emotional needs of children and their families, the authors also address a number of common themes. These include:

■ **A focus on strength and on the common needs and experiences that people with disabilities share with all people; a desire to avoid overemphasis on the disability or related problems.** This sentiment is expressed clearly by Dr. Davila in his essay, in which he cautions against "over-pathologizing" families. J. Elton Moore, in his discussion of issues faced by families of children with low vision or blindness, and Joan Patterson, who talks about "normal children in abnormal situations," also reflect this perspective.

■ **A second theme is that positive emotional health for all family members may be promoted through the use of tangible and emotional support.** Families who have had similar experiences can be an invaluable source of information and support for other families. Some authors also highlight the importance of formal family support services, suggesting ways that they can help families to maintain a balanced family life. Services such as respite care, homemaker services, after-school programs, a job- or recreation-coach help children with disabilities participate fully in community life and address the demands on time, energy and financial resources experienced by families whose children have disabilities.

Photo courtesy University of California Center on Deafness and Mental Health

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■ **The importance of comprehensiveness of services is also evident in many of the articles.** That is, that rehabilitation assessment, service planning and intervention should take into account all aspects of a child's and family's life, rather than being restricted solely to educational and/or vocational goals. In her discussion of traumatic brain injury in children, Betty Pieper also emphasizes the importance of informal support, as well as formal services.

■ **Another lesson is that families have much important information and expertise that can be useful to professionals in understanding the needs of families, and in improving both the content and the delivery of services.** This message is stated convincingly by Marilyn Lash in her discussion of the consultation received by the Research and Training Center at Tufts from families of children with traumatic injury. It is also eloquently demonstrated in Dee Kruger's description of her experiences with seeking appropriate educational and treatment services for her child. **Barbara J. Friesen, Ph.D.**

Barbara Friesen is Director, Research and Training Center on Family Support and Children's Mental Health.

RESEARCH AND TRAINING CENTER
Regional Research Institute for Human Services
Portland State University
P.O. Box 751
Portland, Oregon 97207-0751
(503) 725-4040
National Clearinghouse
(800) 628-1696

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We invite our audience to submit letters and comments.

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FAMILIES IN CONTEXT

There is a tendency to portray persons with disabilities as beset by problems. A good example of this is the all too common newspaper or magazine article where someone is described as "suffering" from a particular disability. However sympathetic, this is essentially a patronizing attitude that creates a lowered standard of expectation and respect.

At the same time, the underlying assumption behind the vast array of social services provided to persons with disabilities and their families is that such persons have extraordinary needs which may require intensive and specialized services. The line between considering persons with disabilities and their families as being beset by problems and having extraordinary needs is extremely thin, and by no means straight. How and where that line is drawn determines the nature and scope of the services they will receive, the expectations that will be placed on them, and the respect they will be afforded.

Consideration of the mental health needs of all persons, including persons with disabilities and their families is a complex and highly charged undertaking. It must be approached prudently in order to avoid numerous pitfalls and unnecessary harm. Persons in the social service field intuitively accept the proposition that children with disabilities and their families are at-risk for incurring "a secondary disability" related to their mental health. They know that insensitive professionals or unresponsive bureaucracies can compound the normal stress and pressure that accompany the search for appropriate services. They are also aware of the subtle and powerful pressures that are sometimes unwittingly exerted by neighbors, friends and relatives in their awkward and self-conscious efforts to interact with a person with a disability or family member.

Despite their awareness, social service professionals can sometimes fail to distinguish between a mental health problem and a person's response to the stress brought on by an uncooperative social service system or the signaling of social stigma. If this distinction is not made, then a new and unnecessary layer of disability is assigned to the lives of persons with a disability and their families, reinforcing the pejorative image of their lives as being beset by problems.

An important safeguard against the misidentification of a mental health problem involves the delivery of appropriate services and social supports. Devoting resources to meeting needs, rather than identifying secondary sets of problems, will almost certainly reduce the stress that persons with disabilities and their families experience. It may also contribute positively to their self-esteem.

Robert R. Davila, Ph.D., Assistant Secretary, Office of Special Education and Rehabilitative Services, U.S. Department of Education.

EMOTIONAL PROBLEMS AMONG CHILDREN WHO ARE BLIND OR HAVE SEVERE VISUAL IMPAIRMENTS

Very little has been written specifically about emotional problems incurred by children and adolescents who are blind or have severe visual impairments. Adolescents and youth who are blind or have severe visual impairments are a highly heterogeneous group whose only common characteristic may be some degree of visual loss. A child's parents and the entire family need to have a clear understanding of the cause, nature, and extent of the visual disability and they must also come to terms with their own feelings before they can effectively meet the physical and emotional needs of their child. Even experienced parents often are filled with doubts about their ability to raise a child who may be blind or have a visual impairment.

When children and adolescents experience vision loss, they experience a wide range of emotional responses including shock, denial, fear, anger, and depression. All of these responses are perfectly normal but also normal is the ultimate acceptance of vision loss and adjustments that allow for an independent lifestyle. An individual's response to vision loss will generally be shaped by a lifetime's experience of responses to other difficult or stressful situations. Those individuals who have coped well with other situations can generally be expected to face vision loss in the same manner. The severity of the impairment and whether it occurred gradually or suddenly may also affect a child or adolescent's response to vision loss.

Infants and young children with visual disabilities have the same needs as all children. Although they are more alike than different from other children, it is the difference in learning style that must be addressed by a specialized educational service.

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Likewise, children and adolescents who are blind or have severe visual impairments have emotional needs consistent with those of sighted children. One study examined the level and structure of fear in visually-impaired and sighted youth and found that youth with visual impairments have quantitative and qualitative differences in their self-reported fears. For example, the ten most common fears of youth with visual impairments and sighted youth were tabulated. While the most common fear among youngsters with visual impairments was being hit by a car or truck, the most common fear of sighted youth involved getting poor grades. Needless to say, additional research is needed on the assessment and treatment of fears and other emotional problems in children and youth who are blind or have visual impairments.

Vision loss affects all aspects of a child's life. Individuals who have experienced vision loss fear that they will be unable to take care of themselves and that they may become the object of pity. Vision loss often threatens the individual's independence, which in turn diminishes self-esteem. When self-esteem is low, it is often difficult to accept assistance offered by others including parents and services from professionals. Individuals with vision loss often need time to adjust psychologically before they are able to begin the rehabilitation process. The amount of time that a child or adolescent will need before they accept their vision loss and are able to benefit from rehabilitation services is a personal matter and may be a matter of days, months, or even years. Social stigma associated with disabilities in general, and with vision loss in particular are difficult to overcome.

Parents and professionals who work with children and adolescents who are blind or have severe visual impairments should be aware of several resources that may be of value in securing needed services. An excellent publication that parents may want to secure is the *Rehabilitation Resource Manual-Vision* which includes a wide array of information on vision loss, as well as the names, addresses and telephone numbers of agencies in each state. The *American Foundation for the Blind Directory of Services for Blind and Visually Impaired Persons in the United States* is another valuable resource. Additional resources may be obtained by contacting the Rehabilitation Research and Training Center on Blindness and Low Vision at Mississippi State University, P.O. Drawer 6189, Mississippi State, Mississippi 39762; (601) 325-2001.

The following publications are available from the Rehabilitation Research and Training Center on Blindness and Low Vision: (1) Graves, W.H., Lyon, S., Marion, S., Boyet, K., (1986). *Career Development Needs of Blind and Visually Impaired Students and Adults*; and (2) Graves, W.H., Lyon, S., Marion, S., Boyet, K., (1986). *Perceptions of Teachers, Rehabilitation Counselors and Rehabilitation Administrators of the Career Development Needs of Blind and Visually Impaired Students and Adults*. **J.Elton Moore, Ed. D.**

Additional Resources:

National Association for Parents of the
Visually Impaired, Inc.
2180 Linway Drive
Beloit, Wisconsin 53511
(800) 562-6265

Rehabilitation Resource Manual-Vision (3rd Ed., 1990)
Resources for Rehabilitation
33 Bedford Street, Suite 19A
Lexington, Massachusetts 02173
(617) 862-6455

Directory of Services for Blind and Visually Impaired Persons in the United States (23rd Ed.)
American Foundation for the Blind
15 West 16th Street
New York, New York 10011
(212) 620-2000

Jan, J.E., Freeman, R.D., Scott, E.P., (1977). *Visual Impairment in Children and Adolescents*. New York: Grune and Stratton.

J. Elton Moore, Ed.D., is Director, Rehabilitation Research and Training Center on Blindness and Low Vision, Mississippi State University.

Preventing Mental Health Problems in Children with Chronic Illness and Disability

Children with special health needs are normal children in an abnormal situation. They have the same developmental needs as all children. In many different ways, however, accomplishing these developmental tasks is made more difficult because of an extra set of demands and hardships associated with the chronic condition. Children with special health needs experience increased stress. Prolonged, unmanaged stress increases the risk for mental health problems. To prevent mental health problems and promote competence, we must achieve a balance between the demands relating to the physical and emotional stress of the illness and the ability to cope with it.

We can promote competence among children with special health needs by providing a nurturing environment within the home, the school, their peer group, and the health care experi-

ences. For example, summer camps for children promote self-confidence. These experiences foster development, improve social skills, increase self-awareness, increase a sense of mastery, and contribute to self-esteem. Sometimes active participation by children in normal activities is discouraged by parents, or teachers due to fears about the child's safety, however, there are many well-supervised programs that minimize these risks.

It is also important to address the needs of parents and siblings. Encouraging parents to invest in the marital relationship by strengthening it is important; a strong marriage is a cornerstone of a competent, nurturing family. Families often report that they have little time for leisure activities because of the extra demands of managing a child with a disability. Yet, families who take time for recreational activities often experience better outcomes in the child and the entire family.

Actively increasing coping skills is another method of preventing mental health problems and increasing competency. In addition to other family needs and tasks parents have the added strain of demands associated with the illness such as: (a) learning about the disability, how to manage it and locate services; (b) managing the treatment and care procedures on a regular basis; and (c) dealing with feelings and emotional reactions to this loss and its consequences. It is not unusual for families to feel overloaded and out of balance in trying to manage normal family life plus the disability. Coping directed at increasing resources, such as getting more services or finding a source of support is one way to reduce the imbalance. Sometimes, parents and children can reduce the overall demands by setting more realistic goals for themselves and not expecting more than is possible. For example, giving up the "supermom syndrome" can reduce strain for many mothers.

Photo courtesy Center for Children with Chronic Illness and Disability.

A second means of coping is by altering meanings. Many demands exist because of expectations. When expectations are not fulfilled, stress levels rise. Parents can, instead, focus on personal growth among family members and their child with a chronic illness. This technique promotes positive and more realistic meanings and goals.

A third way to increase coping is by reducing tension. Exercise, recreation, meditation and other therapies are very effective in bringing the body into a sense of balance and these techniques often renew hope and commitment. Tension reducing programs may be simply having a parent read to a child. Role-playing medical procedures by children is another example of increasing coping skills.

The Mooney Family at Disney World. *Photo courtesy of Brendan Mooney.*

Of all the resources for promoting competency and preventing mental health problems, none has received more attention than social support: emotional, informational and tangible aid. Emotional support assures us that we are loved and valued and that we matter and are connected. Information support helps people solve problems and find services and resources. Tangible aid provides direct assistance—babysitting, running errands, or helping with household chores.

Sources of support are not always automatically available. Parents and children often need to be proactive in seeking and developing supportive relationships, especially when old support networks are unavailable or turn away. Parents can get support from friends, relatives and community groups. Siblings also need support from peers, parents and other community members and, of course, the child with the disability needs this support from peers, adults, and family members.

In working to support families and prevent mental health problems, our primary goal is balance between the challenges and demands facing families and their capabilities for managing them. We cannot change the fact that a child has a disability and we do not know how to cure many chronic illnesses. However, we can work together to improve the quality of services to children with special health needs and their families and to continually strive to achieve this delicate balance.

Joan Patterson, Ph.D.

The text for this article is taken from a paper presented at the March 1990 Parent-to-Parent Conference in Tampa, Florida and prepared by ***Joan Patterson, Ph.D.****, Director of Research, Center for Children with Chronic Illness and Disability, Box 721-UMHC, University of Minnesota, Harvard Street at East River Road, Minneapolis, Minnesota 55455; (612) 626-4032.*

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Families and Children with Traumatic Brain Injury

People have many and diverse "understandings" of how traumatic brain injury (TBI) affects a child. Although many stereotypes exist, especially those that link TBI to congenital retardation or mental illness, the range of behaviors after injury is wide and varied. Not only is each injury unique in kind and degree, but, of course, all human behavior is determined by many factors such as biological/organic, psychological and social. Thus, as each child and each family is different before the trauma of injury, each will be different after.

What is traumatic brain injury or TBI? In the beginning, advocacy groups for people with TBI decided to refer to damage to the brain as "head injury" in order to distinguish the outcomes from congenital brain injury and retardation. This terminology, however, also created some confusion since injury to the head such as broken teeth, bruises and lacerations of the face and skull do not necessarily represent injury to the brain.

The term TBI usually refers to an injury that alters consciousness, if only briefly, and that causes some temporary or permanent damage that adversely affects the individual's preinjury functioning. Usually excluded from the definition of TBI are progressive neurological impairments or impairments present at birth. Usually implied is some sudden onset such as accident, anoxia or stroke.

Often even "minor" episodes cause problems. Unfortunately, medical personnel often fail to perform sophisticated diagnostic testing or to have injured individuals report back for further testing. Problems that arise are often unrecognized as being related to the injury.

How is TBI assessed? Assessment of the injured individual is best conducted by a specialist familiar with evaluation of brain anatomy related to function and how psychological and social factors relate to overall human achievement and satisfaction. A good evaluation will take into account an individual's preinjury history. Generally, the most appropriate specialist is the neuropsychologist. Although the overall intelligence score may be within normal range and even similar to pre-injury, the real life functioning of the person may be seriously affected. An evaluation should include both strengths and deficits and should give some clear and concrete recommendations as to how deficits can be remediated or compensated through the use of strengths.

Planning tools which may be subsequently developed, such as clinical rehabilitation plans and Individual Education Plans should target more than the traditional "learning" behaviors. Such tools should include goals that will broaden and normalize the kinds of behavior and relationships known to affect quality of life. Informal relationships and social supports are to be pursued and valued both for the youngster and the family.

What are some common deficits and related behaviors? Often the difficulties children experience are severely impaired memory for "day to day" events, disinhibition or poor impulse control, agitation, and difficulties in planning and initiating action. The child may have trouble focusing on a task and maintaining his or her concentration. If their symptoms are not recognized as related to an injury, some of these children are likely to be labeled as having attention deficit hyperactivity disorder and may be treated with pharmacological agents.

A certain "slowness" (not related to intelligence) may be noticed by lay people. This involves subtleties in processing and expressing information and feelings and may severely affect communication in general. For example, dysarthria (slow, difficult speech) and/or problems in "word finding" may contribute to psychological frustration for the person. These difficulties often hurt interactions because they are met by lack of patience and tolerance or teasing by others. Physical aftermath such as hemiparesis (weakness of the muscles on one side of the body), poor balance and fatigue are also fairly common and may have some of the same personal and social consequences.

What are some effects related to mental health? Even a limited listing of the possible consequences of TBI demonstrates that these deficits and problems are ones that will cause trouble for a child in academic settings that require recall of facts and respect for structure and routine. The deficits are also at odds with the value our society places upon motivation, problem solving and other executive skills that ordinarily propel one toward becoming a self-starter and independent. Children who have received "mild" injuries or who are in late stages of "recovery" may demonstrate only cognitive and psychosocial difficulties. Their overall dilemma is compounded by the fact that, because they appear "normal" in most ways, they are constantly misdiagnosed and misclassified if they are given any differential treatment at all. Some of their behaviors that stem from one-sided visual field neglect or the failure to "read" social cues or to generalize learning may cause others to see them as uncooperative, lazy, odd, non-compliant, or even manipulative. Often, even in the absence of any preinjury mental health problems, the combination of physical and psychological difficulties presented by the trauma will become troublesome to the child and others. Sensitive and expert intervention is required.

What can be done to help? The child should be seen for careful assessment by a neuropsychologist or other person experienced in TBI. Pharmacological treatment is not the same as for disorders such as attention deficit disorder which may appear similar and biochemical therapy should be approached only through experts with TBI experiences. *Behavioral interventions* should be planned based upon thorough knowledge of behavioral tenets and will include identification of antecedent events, shaping/successive approximation, fading and extinction techniques as well as redirection that does not reinforce the targeted behavior. Positive reinforcement and modeling of what is

expected are critical. The family and school staff need to formulate the plan with the child and be trained sufficiently so that there is consistency in the program. *Family oriented interventions* should be pursued. Trauma to the child is trauma to the family. Intervention should not end with "professional" or "clinical" approaches; support for the informal relationships we all value needs to be a high priority. Ways need to be found to support a typical or preinjury lifestyle and preinjury expectations for both the child and his or her family. Special services such as respite, after school and summer childcare, special transportation, and responsibilities and relationship with friends, neighbors and the community.

Lastly, very real opportunities exist for the prevention of TBI. Homes, schools, and communities must be made aware of the tragic cost of TBI and the many ways we can, in our daily lives, take steps to prevent its occurrence. **Betty Pieper.**

***Betty Pieper**, is Project Director, Model Professional Family Partnerships Grant, New York State Head Injury Association, Inc., 855 Central Avenue, Albany, New York 12206; (618) 459-7911.* *The National Institute on Disability and Rehabilitation Research funded the Model Professional Family Partnerships Grant.*

CHILDHOOD TRAUMA IS TWO STAGE CRISIS FOR FAMILIES

Physical injury to a child inevitably causes emotional trauma for families. Since a primary function of families is to protect and nurture the growth and development of their children, a life threatening and disabling injury threatens the stability and functioning of families at their most fundamental level. Over the past two years, I have been meeting with a parent task force to learn directly from families about the immediate and long-term effects of childhood injury and the adjustment process. The result is a guide for families entitled *When Your Child is Seriously Injured in an Accident...The Emotional Impact for Families.*

Photo courtesy Center for Children with Chronic Illness and Disability

Families describe two stages of crisis following an injury. The first is the accident and the immediate threat to the child's life. Even years later, families can still recall either in stark detail or a blurry haze, the accident and their arrival at the emergency room. Reactions of shock and disbelief among parents are often compounded by reactions of cries and terror among young children. Efforts to calm and reassure them may be hampered by their unfamiliarity with hospital settings, inability to understand the need for painful examinations and procedures, loss of control over their bodies, immersion in medical technology, and the involvement of multiple specialists. Yet the opposite situation of the still and unresponsive child, so severely injured that a comatose condition is present, is painfully similar to death. The waiting period can be so stressful for parents that life seems "suspended in time."

While the emotional impact of childhood trauma should not be compared as greater or less than the diagnosis of a congenital disability or chronic illness, it is the sudden and unexpected event of an accident that results in a disabling injury to a previously healthy child that distinguishes these families. Unlike other conditions that are caused by internal medical disorders, trauma is caused by an external force. Inextricably linked to the effect of such injuries upon families is the fact that most accidents are preventable. All too common examples are motor vehicle accidents that result from children playing in the street, riding bicycles without helmets, or riding in cars without seatbelts or use of child safety seats.

Guilt and anger are two powerful emotions often not discussed directly with parents that need to be acknowledged as normal parental responses to childhood trauma. Yet, when a child is hospitalized, professionals are often reluctant to address the issue of responsibility and prevention, lest they appear accusatory or callous. Yet parents reported intense feelings of guilt that were repeatedly expressed through scenarios of, "If only I had..." that might have prevented the accident. Too often, these issues are not addressed by professionals during the acute care stage of hospitalization, and are suppressed by families for long periods of time. Some parents recalled eventually exploding in rage at spouses, siblings, or children, while others internalized their anger and reported extended periods of self-blame and depression. Destructive cycles of blame and guilt can escalate and further alienate family members; desertion can be physical or emotional. Of note was the comment made by several mothers in cases where the injured child was the eldest son that they thought their husbands had found acceptance of loss more difficult.

The second stage of crisis identified by families is the point of discharge from the rehabilitation hospital when the physical and emotional responsibility for care transfers to the family. A recurrent theme expressed by families was the need for case management, yet the professionals in this role typically terminate services when the child is discharged, when insurance benefits

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are depleted, or when the focus of services shifts from medical to educational or vocational. The difficulties families have finding and coordinating a fragmented and complex service delivery system is often underestimated and misinterpreted by professionals. Furthermore, professionals do very little to prepare families for this role. The frustration and anger expressed by families is too often perceived as dysfunctional reactions to the child's injury and families are too readily labeled as resistant or noncompliant. In reality, a childhood injury affects all members of the family and service plans must recognize the competing demands of various members and needs of families to prioritize.

Marital conflicts present prior to the child's injury were often intensified by the additional pressures of caregiving. New conflicts over discipline often emerged. The needs of siblings were a constant concern for parents who feared that the emotional and physical energy expended on the injured child would result in siblings feeling less loved and attended. Placement of children in pediatric nursing homes or residential educational programs was intensely painful for families.

Despite the complexity of the sequelae following traumatic brain and spinal injuries, discussions over the last year have impressed staff of the Research and Training Center with the resiliency, strengths, and coping abilities of families over time. Professionals may have a biased perspective of these families because they are seen primarily in the immediate post-injury crisis stages of treatment and rehabilitation. Families also reported drawing on their internal and informal support systems first, and used professionals primarily for short-term interventions during critical periods of decisionmaking or severe stress. By meeting with parents as recently as several weeks after their child's injury to as long as ten years post injury, many insights into long-term adaptation by families were gained. The model of using families as experts via a task force is highly recommended to enhance the insights of professionals in order to develop more effective methods of intervention.

Marilyn Lash, M.S.W.

***Marilyn Lash, M.S.W.**, is Director of Training, Research and Training Center in Rehabilitation and Childhood Trauma, Tufts University School of Medicine and New England Medical Center, Boston, Massachusetts.*

Information on ordering *When Your Child is Seriously Injured in an Accident...The Emotional Impact for Families* may be obtained by contacting: Research and Training Center in Rehabilitation and Childhood Trauma, Department of Rehabilitation Medicine, New England Medical Center Hospitals, 750 Washington Street-Box 75 K-R, Boston, Massachusetts 02111; (617) 956-5032.

Children With Deafness and Mental Health Concerns

Children with deafness run a greater risk of suffering serious mental health problems than either children without disabilities or children with other disabilities. This is due both to the etiology of hearing loss, but, especially, to the social experiences associated with hearing loss for young children. Of the five major known etiologies of early childhood deafness, only hereditary deafness is not associated with high prevalence of other disabilities. The other four—maternal rubella, Rh-factor incompatibility, meningitis, and prematurity—are associated with other neurological dysfunctions, which increase the risk of mental health problems for children who are deaf. However, an even greater increase in risk of serious emotional problems for children with deafness comes from non-organic factors.

As has been said time and time again about deafness: the major problem is not the hearing loss itself, but the communication difficulties that almost always accompany prelingual deafness. When a young child is diagnosed as deaf in a hearing family, not only do the parents experience the blend of disbelief, grief, helplessness, anger, and guilt that most parents do upon learning that their infant has a disability, but their feelings are additionally complicated by other factors. Foremost among these is the realization that they cannot take communication with their child, and the language development of their child, for granted. Their child simply will not be able to perceive the speech and sounds that the parents naturally use to communicate, to share and mold experiences and meaning for their child.

After infancy, the basis of most human interaction is language. The diagnosis of deafness suddenly makes all interaction with their child a conscious issue for the parents. The picture is further complicated by the fact that, most often, hearing loss is not diagnosed until the child is in his or her second year of life. This means that, usually, the parents have already developed a good attachment, a positive, loving relationship, with their child by the time the diagnosis is definitively made. Suddenly, with the knowledge that their toddler cannot hear them, the parents feel as if they no longer know how to interact with their own child. This feeling of powerlessness is compounded when they begin to learn about deafness and the controversies over the best way for children with deafness to acquire language: oral-aural versus manual-visual systems, American Sign Language (ASL) versus a variety of English-based sign systems. If the parents choose oral English, even though they know the language system already, English-speech, listening, vocabulary—becomes a chore, lessons to be taught by the parent, learned by the child, rather than a means for communicating. If the parents choose a sign language system, they must learn a new language system

in an unfamiliar manual mode in order to communicate with their child. Either way, language and communication becomes an effort, and a goal in itself-rather than a means for social engagement-for enjoyable sharing of feelings and thoughts. The result is that the quantity and quality of communication for children who are deaf is usually severely restricted, first and most importantly, at home with their family, and later, as well, at school with their peers and teachers. Correspondingly, the quantity and quality of their social experiences is typically narrowed as well. Relationships within the family are easily disturbed, not only between the child and all other family members with whom communication is a chore, but also between other family members as the greater demands of parenting and communicating with the child stress the system in many different ways. It is no wonder that many children with deafness do develop severe socioemotional problems.

What can families do to prevent the development of mental or emotional problems in their children who are deaf? First, and most importantly, they should try to remember that they are parents and not teachers; that the quality of their relationship with their child matters most, not their child's learning English or any other language. In fact, it is more the case that reciprocal, mutually enjoyable social interaction between parent and child stimulates language acquisition than that language is a necessary prerequisite for a good relationship. Parents can also get support for themselves, including an opportunity to express their emotional reactions to their child's disability, and share these with other parents who have children with hearing loss. Families can also try to meet adults from the deaf community, which may help to dispel some of the fears of deafness and anticipated developmental consequences. ***Mimi W.P. Lou, Ph.D.***

Resources for Families Who Have Children With Hearing Loss:

Alexander Graham Bell Association for the Deaf
3417 Volta Place, N.W.
Washington, D.C. 10007
(202) 337-5220

American Society for Deaf Children
814 Thayer Avenue
Silver Spring, Maryland 10910
(301) 585-5400

IMPACT-HI (Independently Merging Parent Associations of California Together for the Hearing Impaired)
2182 Archer Avenue
Fremont, California 94115
(415) 567-4515

John Tracy Clinic
806 West Adams Blvd.
Los Angeles, California 90007
(800) 522-4582

National Association of the Deaf
814 Thayer Avenue
Silver Spring, Maryland 20910
(301) 587-1788

National Information Center on Deafness
Gallaudet University
800 Florida Avenue, N.E.
Washington, D.C. 20002
(202) 651-5051

TRIPOD Grapevine
2901 Keystone Street
Burbank, California 91504
(800) 352-8888

University of California Center on Deafness and Menta Health (UCCD)
3333 California Street, Suite 10
San Francisco, California 94143-1208
(415) 476-4980 (voice)
(415) 476-7600 (TDD)

Mimi W.P. Lou, Ph.D. is the acting executive director of the University of California Center on Deafness and Mental Health.

BEACH CENTER'S SUMMER INSTITUTE ADDRESSES OPTIONS AND CHALLENGES OF YOUNG ADULTS WITH DISABILITIES

"There is life after high school for students with moderate or severe disabilities." That is the message researchers at the Beach Center on Families and Disability will convey at a national conference in Lawrence, Kansas. The *Great Expectations Summer Institute* will provide families and professionals with the opportunity to share how they are responding to the challenges associated with enabling young adults with disabilities to participate in full citizenship after they leave high school. The Institute will be structured to maximize sharing, problem solving and development of personalized solutions and system change strategies regarding students with disabilities. The three day workshop will facilitate: (a) sharing visions of what life after high school could and should be like; (b) discussion of model supports and services that have promise for helping actualize these visions; and (c) development of the next steps needed to put these ideas into practice. For more information on the upcoming June 27-30, 1991 Institute contact: Gary Brunk, Beach Center for Families and Disability, Bureau of Child Research, 3111 Haworth Hall, University of Kansas, Lawrence, Kansas 66045; (913) 864-7600.

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Ours is now a success story, but when my sixteen year old Kate was an infant she was unresponsive, hypotonic (limp), and had crossed eyes. She cried for hours. As a preschooler, she was inattentive and constantly in motion. She talked incessantly. She tore up books, magazines, her clothes, and the house. I was exhausted. A psychologist recommended behavior management, which got us nowhere but made me feel inadequate and more exhausted. Audiologists said she could hear. A neurologist said her chromosomes and brain waves were okay, her reflexes were sort of okay, and he didn't know what had caused the problem. He didn't recommend anything, and seemed annoyed that I didn't have better questions to ask. If someone had asked me to write an articles at that time, it could have been called "What good are neurologists?"

Fortunately, in kindergarten, two smart school psychologists recommended a psychiatrist—a smart psychiatrist—and life slowly began to make sense. He treated the inattention and hyperactivity medically, then talked about behavior management—but as a teaching method, not a cure. Other behaviors included head pounding and inability to get to sleep or sleep through the night, and he treated these with an antidepressant and, eventually, lithium. It took quite a long time, but these symptoms gradually came under control.

Her school placement in a program for children called "educable mentally retarded" (EMR) wasn't working, but when a class for children called "emotionally disturbed" was suggested, I panicked. What did that mean? After talking to many friends and advisors, I reluctantly agreed. It was a good decision; Kate spent second and third grades with a wonderful teacher, really beginning to learn. Regardless of her disabilities, her strengths had long included a wonderful vocabulary and a sly humor, and she continued to delight people with these. Kindergarten example: Teacher: "I like your sweater, Kate." Kate: "Do you mean my *cardigan*?" Fifth grade, in sex education class: Teacher: "Has your mom talked to you about that?" Kate: "My mom doesn't *know* about that."

Dee and Kate Kruger

Since fourth grade Kate has been back in an EMR class, and is now a sophomore. She's integrated into the high school, taking regular physical education, ceramics and history. She works two mornings a week in a restaurant and is learning to do housework, make appointments, and keep a checkbook. She's little short of fabulous at using the bus system.

What's her diagnosis? Attention deficit-hyperactivity disorder? Mood disorder? Mental retardation? Cerebral palsy? "Autistic-like behavior"? Yes to all of the above, at this point gathered under the umbrella of pervasive developmental disorder. Whatever it is, she's funny, enthusiastic, highly motivated to learn, and interested in typical teenage pursuits.

I had thought that Kate's experience was fairly typical of children with both developmental and psychiatric disorders-that because of the close scrutiny of many professionals, any psychiatric problems were more likely to be identified early in children with developmental problems. I learned recently that this isn't necessarily true. "Kevin" is a young man we know through Kate's after-school activities. He is in a wheelchair, uses a communication board, and is subject to seizures and cluster headaches. In my casual contact with him he had always seemed friendly, likeable, and remarkably interested in learning.

However, Kevin's mother Mary recently told me that he, too, has been depressed, angry, and unable to concentrate. School personnel recommended therapy, and for years Kevin went to a counselor who was known for working with children with disabilities. Mary isn't sure exactly what they talked about, but it made some sort of sense that Kevin would be depressed and angry about his situation. But therapy didn't seem to be accomplishing anything. Kevin continued to get more and more depressed and angry. He punched and scratched his mother. He continually referred to death and wanting to die.

Kevin's neurologist at last recommended a psychiatric evaluation, and Kevin's problems began to be addressed. Treat-

Next Issue: Focus on Gay and Lesbian Youth

The next issue of *Focal Point* will address the topic of lesbian and gay youth. We will describe the isolation many such youth experience as well as the increased risk some gay and lesbian youth are at for depression, suicide, and other problems. This issue will also discuss the impact on the family upon disclosure or discovery of their child's homosexuality and will describe the experiences of gay families seeking services for their children with serious emotional disorders. Model programs providing services to lesbian and gay youth and their families will be described.

ment has been complicated because of his seizures and headaches, but it has been successful, and Kevin is much better. He's been able to concentrate in classes, even finishing hour-long exams. He can identify which antidepressant works best for him. His preoccupation with death has ended. Mary is relieved that Kevin's unhappiness can be understood and helped, and that she, the neurologist, and the psychiatrist have been able to work as a team.

I understand that children and adults with developmental problems often also have behavior problems. It's certainly plausible to see these, or apparent emotional problems, as secondary to developmental disabilities. However, knowing the experiences of these two children, I hope that the possibility of biological psychiatric problems will increasingly be considered by clinicians working with people who have developmental disabilities. **Dee Kruger.**

Dee Kruger is on the board of directors of Wisconsin Family Ties in Madison, Wisconsin and is the editor of the Wisconsin Family Ties *newsletter.*

New Developments Increase Access to Supplemental Security Income (SSI) Benefits for Children With Disabilities

Two recent developments may increase the access financially needy children with disabilities have to Supplemental Security Income (SSI) benefits. The first development increases funding opportunities for children with a variety of disabilities and the second enhances opportunities for children with mental, emotional, and behavioral disorders. Further, a new program has been established to assist parents in negotiating the Supplemental Security Income system.

In a February 1990 United States Supreme Court case, *Sullivan v. Zebley*, 110 S.Ct. 885, 107 L. Ed. 2d 967 (1990), the Court found that the Social Security Administration's regulations for evaluating disabilities were more restrictive for children than for adults. Accordingly, as a result of this disparate treatment of children and adults, in some cases child claimants were denied benefits; yet, upon turning eighteen, were awarded benefits on the basis of the same impairment which was insufficient to qualify the youth for child disability benefits. In light of the *Zebley* decision, in February 1991 new regulations were announced to determine whether a child has a disability for purposes of Supplemental Security Income benefits. A child may be found to have a disability: (1) if his or her condition appears in the Administration's listing of impairments; (2) or if the child has a condition as functionally or medically as serious as one of the listed impairments; (3) or if the impairment prevents a child from performing age-appropriate activities. The third criterion requires an individualized, functional analysis of the impact of an impairment on children who have filed disability claims. As the United States Supreme Court explained, this means that an inquiry will be made into the "impact of an impairment on the normal daily activities of a child of the claimant's age-speaking, walking, washing, dressing, and feeding oneself, going to school, playing, etc." *Sullivan v. Zebley*, 110 S.Ct. at 896. Children who were denied SSI after January 1, 1980 may, if they meet eligibility standards, receive SSI payments as well as benefits back to the initial date the child applied for benefits.

Secondly, in December 1990 the Social Security Administration revised and expanded its list of childhood mental impairments. New additions to the children's list include attention deficit hyperactivity disorder; personality disorders; somatoform, eating, and tic disorders; anxiety disorders; psychoactive substance dependence disorders; autistic disorder and other pervasive developmental disorders; and, developmental and emotional disorders of newborn and younger infants (birth to age one). Children who have one of these listed conditions have a disability for purposes of eligibility for Supplemental Security Income.

The National Parent Network on Disabilities has, through a cooperative agreement with the Social Security Administration, launched a new program (1) to provide national outreach to parents about their children's possible eligibility for Supplemental Security Income and (2) to provide training of parent volunteers to assist other parents to negotiate the system. The two model demonstrations of parents helping parents will occur in Philadelphia and Kansas City. To locate trained parent leaders in each state who can assist families in accessing the SSI system contact: National Parent Network on Disabilities, 1600 Prince Street, Suite 115, Alexandria, Virginia 22314; (703) 684-6763. To locate the closest Social Security office contact the Social Security Administration at (800) 234-5772.

NATIONAL CLEARINGHOUSE ON FAMILY SUPPORT AND CHILDREN'S MENTAL HEALTH
Portland State University
P.O. Box 751
Portland, Oregon 97207-0751
(800)628-1696

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PARENTS' PERSPECTIVE

He, I and We
He came into this world five weeks early
I was glad to have a son
He was hospitalized with croup when seven months old
She stayed with him at the hospital
The first thing in life he remembers is
breaking the sugar bowl lid
She said she knew it would be
He was kicked out of two private schools in kindergarten
I'm glad public school is free
He loves the outdoors
I like to take him camping
He wanted to go to my Rotary picnic
I had to carry him off before he hit his brother with a bat
He pays me a dollar every time I catch him smoking
I've put over twenty dollars in his "money jar" (He's ten)
He's the best Nintendo player in the family
I look for anything he can excel in
He makes a wonderful witch on Halloween
I can't think of a more appropriate character
He loves to help and will mow, rake or clean all day
I have to give him directions, or he's totally lost
He loves to antagonize and fight with his brother
We have a permanent dent in the wall
from his brother's head
He has no friends
My other son is the most popular boy in school
He's never invited anywhere
I sometimes dump him on his grandparents
He wants to be a helicopter pilot, or else wax floors
I wonder what his adult life will be like
He blames some of his problems on being "in ED"
I wish he could get along with "normal" kids
His brother tells all of us he wished he didn't live with us
My other son is gifted, and knows what's going on
When he's asleep in his bed, he looks
like any "normal" person
I look at him when he's asleep and I cry
He didn't choose to be this way
I'm glad I have a son

Danny Amrine, Tulsa, Oklahoma, Research and Training Center National Advisory Committee Member.

Editor's Note: Parents are invited to submit contributions, not to exceed 250 words, for the *Parents' Perspective* column.

WHY NOT?

Parents of children with emotional disabilities often serve as the managers of their children's care, sometimes by choice and in other instances because no formal case management services are available. Additionally, case management or other service-coordination mechanisms do not guarantee that appropriate resources will be available for the child and family, nor do they assure that the family has choice about the nature of the assistance they receive.

In Illinois, an innovative family assistance program reverses the usual ways of thinking about service access, financing, and the provision of case management services. Families are provided with a monthly stipend of about $400 per month to spend "for the care of their child who is living at home." Families who want their children to return home from out-of-home placement receive one extra payment to prepare for the child's return home. Receiving the family assistance benefit does not disqualify the child or family from services for which they would ordinarily qualify, for Supplemental Security Income (SSI), or for public assistance. In addition, the stipend is tax-free. This pilot program is modeled on a family assistance program in Michigan and is being carefully evaluated by researchers from the Chapin Hall Center for Children at the University of Chicago.

Families may choose to receive information and assistance in locating services from an agency-based service facilitator. This service is provided initially at no cost; after an introductory period, the family may elect to use part of their family assistance stipend to continue the service facilitation services, or may choose to manage their own services and family support plan.

This approach appears to have many positive features: it puts the family in charge of its own service plan, while preserving the option of formal case management; it provides practically unlimited options for families to define and obtain needed family support and other services; and it provides incentives and support for the child and family while the child is living at home.

This issue merits two "why nots." First, rather than sinking most resources into expensive out-of-home services and providing support only to foster families or to families when placement is imminent, all states could develop programs that support children in their own homes and provide incentives for the development of community-based services. Second, research should not only compare various case management models with each other, but should contrast formal case management with approaches such as the Illinois program.

Why not direct resources to families and expand family choice about the nature of the assistance they receive and the roles they wish to play in managing their children's care? Why not carefully examine how well these good ideas work? B.F.

Editor's Note: Readers are invited to submit contributions, not to exceed 250 words, for the *Why Not?* column.

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